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Experiences of siblings of children with physical disabilities: an empirical investigation

INEKE M. PIT-TEN CATE†* and G. M. P. (INEKE) LOOTS‡

† University of Southampton, Centre for Research into Psychological Development, Department of Psychology, Highfield, Southampton SO17 1BJ, UK

‡ Free University, Faculty of Psychology and Pedagogics, Van der Boechorststraat 1, 1081 BT Amsterdam, The Netherlands

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Abstract

Purpose: This study aimed to investigate the experiences of Dutch siblings of children with physical disabilities ($n = 43$).

Method: Interviews were conducted to investigate experiences of siblings in 3 areas: the sibling relationship, the relationship with parents, and the relationship with others. The siblings also completed a coping response inventory.

Results: The siblings reported difficulties in undertaking activities and in communicating with their brother/sister with a disability. Most siblings worried about the future and the health of their brother/sister with a disability. The siblings reported open communication and trust as the main characteristics of the relationship with their parents. They acknowledged their parents' attempts to treat all children equally, although parents were not always successful in doing so. Having a sibling with a disability did not cause problems in the relationship with friends. The awkward reactions of strangers caused the siblings much annoyance and distress. Siblings in this sample used more approach coping strategies than avoidance strategies, $t(34) = 2.37, p < 0.05$.

Conclusion: The brothers and sisters generally did not experience many significant problems, however, a minority of the children did experience problems for which they would like help. In addition, they reported joys as well as problems.

Introduction

There is considerable literature on family adaptation after the birth of a child with a disability, which has primarily focused on the parents. Research on siblings, however, is less extensive and results are inconsistent. The sibling relationship is unique in its permanency and therefore has a major influence on several aspects of personal development.^{1,2} Lobato identifies three functions of typical sibling relationships: the developmental importance; influences on relationships and experiences with others; and the dissemination of information.³ Although it is often assumed that the

character and influence of the sibling relationship change as one of the siblings experiences physical or mental delays, controversy regarding the specific impact of a disability or illness remains. Most research in this area has focused on siblings of children with mental disabilities, while research regarding experiences of siblings of children with physical handicaps remains sparse.⁴ While most studies support the notion that siblings of children with special needs experience more problems in psychological adjustment than siblings of non-disabled children, some positive outcomes have been reported as well.⁵ Lobato *et al.* conclude that there is no uniform relationship between a child's impairment and psychological maladjustment of his/her siblings. The impact of a child's impairment on siblings may be best conceptualized as a risk factor, the significance of which is mediated by socio-demographic features, individual and family adaptive and functional patterns, sibling constellation variables, and impairment characteristics.⁶

Several studies point out that siblings of children with disabilities are more anxious and more withdrawn or depressed than siblings of non-disabled children.^{7,8} Other studies report that siblings of children with disabilities express more aggressive behaviour and experience more difficulties in social and peer relationships.^{9–11} Furthermore, the occurrence of more psychosomatic illnesses and problems in school have been reported.¹² Mixed findings have been reported regarding differences in outcome for brothers and sisters. Gath has studied the family background of children with Down's syndrome over several decades. In 1974 she reported that in particular older sisters in those families where there were problems like deprivation and social disadvantage were at risk for emotional and behavioural problems, in particular at school. It was suggested that these girls could be carrying an undue burden of care. However, this finding was not replicated in a later study. In this study no differences were found between scores on the

* Author for correspondence; e-mail: ip@soton.ac.uk

Rutter behavioural scale for brothers and sisters nor between older and younger siblings.^{13,14} In contrast to these reported negative outcomes, positive outcomes have been described as well. Several studies suggest that siblings of children with disabilities are more social, more tolerant, show more altruistic behaviour and have a better self concept (see ⁴ and ¹⁵ for a review). Lobato outlines the range of potential positive and negative effects of a child with a disability or chronic illness on his/her siblings.³ Potential positive feelings or characteristics associated with being raised with a child with a disability include increases in maturity, responsibility, altruism, tolerance, humanitarian concerns and careers, sense of closeness in the family, self confidence and independence. Potential negative outcomes include feelings of parental neglect, feelings of resentment, perceived parental demands and expectations for achievement, embarrassment, guilt about own health, extra responsibilities in the home, restrictions in social activity and sense of distance in the family. Sometimes there seems to be a narrow distinction between positive and negative effects: although altruism and development towards humanitarian concerns and careers may certainly be seen as positive, here lies a risk for an unhealthy development too. Crittenden describes the possibility of a compulsive caregiving by children of caregivers who are themselves withdrawn. The children may learn to use false positive affect to elicit attention without making any demands that might cause the parent to retreat further psychologically.¹⁶ Siblings are reported to experience the full range of emotional effects and many different factors seem to contribute to an overall feeling of either having benefited or been harmed by the specific family situation. Family characteristics as well as characteristics of both siblings appear to be important factors contributing to sibling adjustment.^{4,5} Although results are not uncontested it seems that siblings fare better when: (1) the family is larger; (2) the socio-economic circumstances are better; (3) the parents have a more positive attitude towards the child with a disability; (4) the siblings are younger than the child with a disability; (5) the age difference between siblings is greater; (6) the child with a disability is still young; and (7) the disability is less severe.^{4,5,17}

In describing potential sources of stress in siblings of children with a disability, Gamble and Woulbroun distinguish between stressors in the sibling relationship, stressors in the parent-child relationship and stressors in relationships with peers and interactions with the larger community.¹⁸ Sources of stress in the sibling relationship include problems associated with meeting affectional needs, providing direct services and developing an

identity. Themes in the parent-child relationship include inadequate communication, discrepant expectations and perceptions, parental attitudes and practices, and parental personal adjustment. Finally, stressful themes associated with the relationship with peers and interactions with the larger community include informing friends, guarding the child with a disability against discrimination, feelings of shame, and isolation of the family. It should be noted that not all siblings of children with disabilities experience all circumstances just described. Therefore, the potential stressors should be evaluated for the extent to which they determine sibling adjustment. Furthermore, coping attempts directed towards the avoidance, elimination or reduction of stress buffer the potential negative effect which stressors may have on the siblings' physical, psychological and social well-being.¹⁹ This may explain why some siblings claim to suffer from their specific family situation, while others state that they have benefited.

The parents' attitude toward the child with a disability is an important factor in sibling adaptation. The way in which parents cope with raising a child with a disability in part determines the sibling adaptation. For example, Daniels *et al.* found that children with juvenile rheumatic diseases and their siblings experience more psychological and physical problems when their parents suffer from depression or other medical symptoms. Yet, they found that positive adaptation of both the child with the disease and the siblings is facilitated by family cohesion and open communication.²⁰ Furthermore, several studies suggest that parents' demonstrated acceptance of the child with a disability as well as conveyed positive attitudes are often adopted by siblings, and are therefore of importance in sibling adaptation.^{13,21}

Differential treatment of the children is also considered a factor influencing sibling adaptation. Studies have found a positive relationship between differences in parental treatment and psychological functioning of the children.^{5,22} Von der Dunk found that siblings of children with spina bifida often develop feelings of neglect as a result of the amount of parental attention and care for the child with a disability.²³ Similarly, Quittner and Opipari conclude that siblings of children with cystic fibrosis are at risk for experiencing the negative effects of differential treatment, as their mothers not only spent more time with the child with the illness but also rated this time as more positive than time spent with the healthy sibling.²²

It is not clear that findings from samples of families of children with mental disabilities can be generalized to families with physical disabilities. Physical and mental disabilities may produce different demands to families

and may therefore have different effects on family life.²⁴ Furthermore, it is not clear that findings from samples in one country can be generalized to other countries. Many studies were conducted in the United States. As there are clear differences in culture, laws and health care services experiences of families of children with special needs are expected to be different in the Netherlands. The present study was conducted in response to parental queries with the Dutch Society of Children with Physical Disabilities and their Parents (BOSK) regarding the 'other' children in the family. The study aimed to describe how Dutch siblings perceive their lives to be affected as a result of being raised in a family with a child with a disability. The following research questions were addressed: (1) to what extent do the brothers and sisters experience problems in relationship with their disabled sibling, with their parents and with peers and external community; (2) is there evidence to suggest that the presence of the disabled child in the family leads to undue demands on the brothers and sisters by their parents; and (3) is there evidence of the presence of protective factors as mentioned in the literature?

Method

SUBJECTS AND PROCEDURES

A letter was sent to a random sample of one hundred and fifty families who are members of the BOSK. In order to be considered for inclusion in the study the family needed to include a child with spina bifida, cerebral palsy or multiple impairment as well as a non-disabled child aged 10–18 years. The letter briefly explained the study and what would be involved if they agreed to participate. The parents were asked to complete a global family checklist (GFC) regardless of their willingness to participate. This checklist contains questions about family composition and level of dependency of the child with a disability. Sixty nine families responded, of which forty six agreed to participate. Of the 46 families, three families were not included in the sample, one because the sibling did not meet the age requirements and two due to time limitations, reducing the subject pool to 43. Demographic characteristics of the families are presented in table 1.

The mean age of the target siblings was 14.1 years ($SD = 2.52$), ranging from 10–19 years. The mean age of the children with a disability was 13.2 ($SD = 2.70$), range 5–18 years. Twenty-six (60.5%) siblings were older than the child with a disability, 15 (34.9%) younger and 2 (4.7%) of the same age. All siblings attended full-time regular education. Parents rated the functioning of the

Table 1 Frequency and percentage distributions for the demographic variables

Variable	Frequency	% ^a
Siblings		
Brothers	15	34.9
Sisters	28	65.1
Child with disability ^b		
Male	21	47.7
Female	23	52.3
Disability ^b		
Spina bifida	18	41.9
Cerebral palsy	11	25.6
Multiple impairment	14	32.6
Family		
Father, mother, son(s), daughter(s)	30	69.8
Father, mother, sons	4	9.3
Father, mother, daughters	9	20.9
Mother, son(s), daughter(s)	3	7.0
Education of child with disability ^b		
Regular education	12	27.3
Special education	23	52.3
Day centre	9	20.9
Residence of child with disability ^b		
Home	37	84.1
Institutional setting	7	15.9

^a Percentages may not add to 100 due to rounding.

^b $n = 44$ by inclusion of twins.

child with a disability on 'eating', 'dressing', 'personal hygiene' and 'toileting' using a 3 point scale, (0 = independent, 1 = help needed, 2 = dependent). The scores on the four items were summed and this total score was used. The mean score was 4.2 ($SD = 3.14$, range 0–8). Sixty one% of the fathers and 39% of the mothers had received education at university level. Fathers worked an average of 39.7 hours a week ($SD = 7.28$), mothers an average of 11.6 hours ($SD = 10.86$). The 43 families of the sample did not differ on measures of the GFC, except for family composition, when compared to the 26 families not able or willing to participate.

All siblings were contacted by phone and an interview was scheduled. The interviews were held at the sibling's home. Before the interview started the interviewee was asked to give his/her consent, agreeing to take part in this study and agreeing to allow the interviewer to tape record the interview. After completion of the sibling relationship interview (BRI), siblings aged 12–18 years were asked to describe a stressful situation they had experienced over the last 12 months associated with their sibling with a disability before filling out the coping response inventory-youth form (CRI-YF).²⁵

MEASURES

Global family checklist (GFC)

The GFC is a checklist developed for this study and consists of questions regarding family composition, the children's ages and where the child with a disability lives. Furthermore, some questions regarding the level of dependence of the child with a disability are included.

Sibling relationship interview (BRI)

The BRI is a semi-structured interview for siblings of children with disabilities which was designed for this study. It was used to investigate positive and negative experiences of these siblings in their relationships with others. The interview contains questions regarding the sibling relationship (12), the relationship between the siblings and their peers and external community (9), and between the siblings and their parents (7). The interview also contains questions regarding adopted solutions and the need for assistance in dealing with stated problems (practical or relational). Finally, a question regarding the extent to which siblings worry about their brother/sister with a disability is included. Based on the answers, categories were defined for each question. All answers were then independently coded by two psychologists before further analysis. Inter-rater reliability ranged from 72–98% agreement with a kappa ranging from 0.60–0.96.

Coping response inventory-youth form (CRI-YF)²⁵

The CRI-YF may be used for assessing healthy youth as well as youth with psychological, emotional, or behavioural problems or medical disorders, aged 12–18 years. For the purpose of this study the CRI-YF was translated into Dutch and administered in a self-report format. The original norms were applied. The instrument includes 10 items that provide information on how the respondents appraise the stressor and its outcome. Furthermore, the CRI-YF consists of 8 scales which each measure different coping responses to stressful events. Four scales: Logical Analyses (LA); Positive Re-appraisal (PR); Seeking Guidance and Support (SG); and Problem Solving (PS), measure approach coping. The other four scales: Cognitive Avoidance (CA); Acceptance or Resignation (AR); Seeking Alternative Rewards (SR); and Emotional Discharge (ED), measure avoidance coping. The first two scales in each set, LA, PR, CA and AR, measure cognitive coping strategies. The third and fourth scale in each set, SG, PS, SR and ED measure behavioural coping strategies. Each scale

contains six items. The respondents rate their reliance on the 48 coping strategies using a four-point scale (ranging from 0 'not at all' to 3 'fairly often'). Raw scores for the eight sub-scales can be transformed into standard scores. For the purpose of this study, total scores for the use of 'approach' and 'avoidance' strategies were computed by summing the raw sub-scale scores (LA, PR SG, PS and CA, AR, SR, ED, respectively).

Reliability and validity of the inventory is well established. Alpha internal consistency coefficients ranging from 0.55–0.70 are reported in the manual. Average test-retest reliability coefficients of 0.29 for boys and 0.34 for girls are reported. The manual also outlines research supporting the predictive and discriminant validity of the inventory.

Results

The primary aim of this study was to investigate experiences of brothers and sisters of children with physical disabilities. The BRI was organized around the following themes: the sibling relationship, the relationship between the siblings and peers and external community, the relationship between the siblings and their parents, adopted solutions and need for assistance, and worries. The results will be presented accordingly.

THE SIBLING RELATIONSHIP

When asked to describe the impairment of their brother or sister with a disability, most siblings named the cause (birth defect, infection) and/or characteristics. The respondents described their sibling with a disability mostly as 'funny' (41.9%), 'cheerful, spontaneous' (32.6%) or 'pleasant' (27.9%). Less liked traits were 'difficult behaviour' (37.2%), 'pushy' (20.9%) or 'inabilities' (20.9%).

Siblings were asked to name pleasant and unpleasant experiences in relation to having a brother or sister with a disability. Most positive experiences had to do with material 'extras' the respondents received associated with their sibling with a disability. Examples included jumping the queue at amusement parks, living in an adapted (and as a result, often a new and large) house and going on special holidays. Furthermore, siblings reported to enjoy doing things together with their disabled brother or sister, e.g., building with lego blocks, playing hide and seek and computer games. Other positive experiences mentioned had to do with the increase in their own insight. Siblings reported that they had acquired a different perspective regarding other people, especially people with disabilities. Unpleasant

experiences included difficulties when doing things together and communication problems. Outdoor games especially, e.g. playing tag, football, or skateboarding proved to be difficult when a sibling has a disability. When faced with difficulties one third of the siblings (32.6%) preferred to choose other activities instead of struggling to find solutions. Others changed their own behaviour, adapted the game or helped the child with a disability. Not surprisingly, however, siblings try harder to find an adaptation for the activities they like than for disliked activities. Twenty-five siblings found solutions for activities they liked, while only twelve found solutions for less preferred activities.

Although most of the interviewed adolescents stated that they and their siblings with a disability could understand each other, two-thirds of the subjects indicated that this was not always without difficulty. Most problems are a result of speech impairments, the cognitive level of the child with a disability or differences in interests. Siblings primarily talked about topics regarding everyday affairs, e.g. what happened in school or on television programmes. The disability itself was a much less frequently discussed topic. Nearly half of the respondents reported that they did not talk about it at all. The topic was avoided largely because the siblings did not know how to broach the subject, did not know what to say, or because the child with the disability preferred not to talk about it.

Most siblings (83.7%) quarrelled, often about trivial things, however, they reported having a lot of fun with their brother or sister with a disability as well. Seven siblings (16.3%) indicated that they were not able to argue due to limitations of the child with a disability. As annoying as little arguments with a sibling can be, not being able to quarrel seems even more distressing. As one respondent stated 'some peers always complain about the quarrels with their siblings, but I often wish I could quarrel'.

RELATIONSHIP WITH PEERS AND EXTERNAL COMMUNITY

In this study there were no indications of complications in peer relationships associated with having a sibling with a disability. All respondents had told one or more of their friends about their sibling with a disability. However, some had chosen not to tell everyone because they felt it was not their concern (19.1%) or because they were afraid that others would react in an unpleasant way, e.g. by teasing (9.5%). In most cases the (best) friends knew the child with a disability. The peers responses were mostly described as 'normal'. These friends were interested (37.0%) and/or felt sorry for the child with a

disability (38.0%). Few peers responded in a teasing way (4.6%). Responding by asking questions was appreciated most by the interviewed siblings. When friends visited the home they behaved 'normally' around the child with a disability, although at first some did not know how to react. Some behaviour still offered room for improvement, i.e. peers should behave more naturally and not try to make a fuss over the child with a disability.

Most brothers and sisters (67.4%) found it 'normal' to go out with their sibling with a disability, although they did not always like it. Sometimes they were troubled when others saw or knew things about the disabled child, like incontinence (16.3%) or external characteristics (16.3%) e.g. scars, or 'strange' behaviour (11.6%). There were often reactions from outsiders. People largely reacted by looking and staring (55.8%), while some showed pity/compassion (16.3%) or offered help (4.6%). There were also strangers who reacted in a 'normal, positive way'. The siblings took the view that the behaviour of strangers was certainly open to improvement. They thought that people should be better informed, should behave more 'naturally', show more respect, and certainly refrain from staring.

RELATIONSHIP WITH PARENTS

Although the youngsters accepted the fact that the child with a disability gets more attention from the parents, they do not always like the situation. Most respondents acknowledged that their sibling needed extra attention and care and therefore went along with it, however, 9 (20.9%) would have liked to see a change. At a later stage during the interview the subjects were asked if they had experienced differences in the way the parents treated both children. Most answered that there was in fact a difference. When asked about things the siblings did not appreciate about their parents, many (44.7%) responded that they disliked the fact that their parents tended to 'go on about' completing their homework, cleaning their room and staying out too late. Some of the children (14.3%) mentioned again that they did not like it when the parents spent more time with the youngster with a disability.

Although most siblings noticed differences in parental treatment, a remarkable number of siblings (65.1%) spontaneously indicated that they very much appreciated their parents' attempts to be equitable. Other points in the relationship with parents that merited appreciation were open communication (31.4%) and time spent doing things together (34.3%). The relationships in many families were characterized by trust and open communication. The interviewees felt they could tell every-

thing to at least one of the parents. They also discussed the child with the disability, sometimes in their presence, but mostly with parents alone. The siblings indicated that they wanted to support their parents in caring for their brother or sister with a disability. They often helped with household activities and took part in caring for the child with a disability as well. Helping could be fun, depending on what has to be done. In general, the siblings regarded helping as a normal activity. Parents were said to show appreciation of the siblings' assistance.

SOLUTIONS FOR PROBLEMS; THE NEED FOR ASSISTANCE AND WORRIES

Nearly half of the siblings had asked for or received help with respect to their interaction with the child with a disability. This help was mostly given by the parents, but also by external figures like teachers and psychologists from a bureau of mental health. Most respondents did not feel in need of help, but 9 (20.9 %) indicated that they would like help, primarily in the form of information. A remarkable number of siblings (75.4%) worried at times about their brother or sister with a disability. The worries usually concern the future (36.5%) and the health (26.8%) of the child with a disability.

DEMOGRAPHIC CHARACTERISTICS

Chi-square analyses were used to investigate the role of demographic variables including age of sibling, birth rank and disability. No significant relationship was found between age and BRI answers. Only one variable was related to birth rank, i.e. differential treatment was most often reported by siblings who were older than the youngster with a disability $\chi^2 (1, n = 43) = 5.59, p < 0.05$, Cramér coefficient $V = 0.37, p < 0.05$. Chi square analyses revealed an association between disability category and the frequency with which solutions for problems are found, $\chi^2 (1, n = 43) = 4.29, p < 0.05$, Cramér coefficient $V = 0.32, p < 0.05$, i.e. siblings of children with multiple impairments had more difficulties in finding solutions than siblings of children with spina bifida or cerebral palsy. Furthermore an association was found between disability category and the wish for changing the relationship with parents, $\chi^2 (2, n = 43) = 7.26, p < 0.05$, Cramér coefficient $V = 0.41, p < 0.05$. Specifically, none of the siblings of a child with a multiple impairment wanted to change the way their parents relate to them, while siblings of children with spina bifida or cerebral palsy had mixed opinions. Finally, an association was found between disability category and

the need for help, i.e. most help is wanted by siblings of children with spina bifida $\chi^2 (1, n = 43) = 6.03, p < 0.05$, Cramér coefficient $V = 0.38, p < 0.05$.

COPING STRATEGIES

Before completing the CRI-YF siblings aged 12–18 years were asked to think back to a stressful (unpleasant) situation associated with the brother/sister with a disability over the last 12 months. The siblings then answered 10 questions regarding how they appraised the stressor and its outcome. Next, they completed the 48 coping items. Descriptions of a stressful situation included illness or hospitalisation (32.6%), worries about the present or future (30.2%) or reactions by other people, e.g., pestering, staring (14.0%).

Scores on the evaluation items showed that 20 (57.1%) of the respondents had experienced a similar situation before. Twenty (57.1%) anticipated something like this would happen and 16 respondents (45.7%) felt they had had enough time to prepare for the situation. Thirteen (37.2%) siblings had wondered whether the situation could have a negative effect on them and only 6 (17.1%) found the experience challenging. Remarkable is the fact that all respondents stated that the problem was not raised by themselves; 17 (48.5%) said that the problem was originated by others; and 16 could not point to a cause. Finally, 26 (74.3%) siblings reported the problem had been resolved.

The pattern of the use of coping strategies by children in this sample is no different from that of other youngsters in this age group: siblings in our sample used all coping strategies at an average level compared to the norm group (table 2).

Pearson correlation coefficients were used to investigate the role of age. No significant correlations were found except for the correlation between age and the use of the coping strategy 'logical analyses' ($r = 0.34, p < 0.05$). *T*-test results revealed that the siblings use more approach than avoidance strategies, $t(34) = 2.37, p < 0.05$. Furthermore, differences between brothers' and sisters' use of coping strategies were found. Sisters scored higher on 'total approach' $t(33) = 2.52, p < 0.05$, as well as on the sub-scales 'logical analysis', 'emotional discharge' and 'seeking guidance and support' when compared to brothers (table 2). Further comparisons showed that siblings who would like a change in the relationship with their parents scored higher on 'total avoidance' than other siblings, $t(33) = 3.40, p < 0.01$. Siblings who would like to see a change made more use of the coping strategies 'acceptance or resignation', 'seeking guidance and support' and 'emotional dis-

Experiences of siblings

Table 2 Descriptive statistics and *t*-values for the Coping Response Inventory-Youth Form^a: comparing brothers and sisters

	Total (<i>N</i> = 35)		Brothers (<i>N</i> = 14)		Sisters (<i>N</i> = 21)		<i>t</i> <i>df</i> = 33
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Approach responses							
Logical analysis	48.1	9.51	44.0	8.65	50.8	9.23	−2.19*
Positive reappraisal	51.1	6.95	50.2	5.96	51.8	7.61	−0.64
Seeking guidance & support	48.6	8.10	42.3	4.88	52.8	7.04	−0.86**
Problem solving	47.2	9.58	46.0	10.75	48.0	8.89	−0.60
Total approach (raw score)	29.9	11.97	24.1	8.94	33.8	12.34	−2.52*
Avoidance responses							
Cognitive avoidance	45.9	7.94	45.4	6.77	46.2	8.79	−0.27
Acceptance or resignation	50.1	9.15	52.0	8.44	48.8	9.57	1.03
Seeking alternative rewards	49.7	9.92	47.4	9.32	51.3	10.21	−1.17
Emotional discharge	48.7	9.95	44.6	6.24	51.5	11.08	−2.13*
Total avoidance (raw score)	25.1	12.46	22.9	10.02	26.5	13.90	−0.85

* $p < 0.05$. ** $p < 0.001$.

^a Standard scores ($M = 50$ $SD = 10$) for the 8 sub-scales of the Coping Response Inventory-Youth Form.

Table 3 Descriptive statistics and *t*-values for the Coping Response Inventory-Youth Form^a: comparing siblings who do or do not want to change the relationship with their parents and siblings who do and do not worry

	<i>Siblings who want their relationship with parents:</i>					<i>Siblings who</i>				
	<i>to change (N = 7)</i>		<i>not to change (N = 28)</i>		<i>t</i> ¹	<i>worry (N = 26)</i>		<i>do not worry (N = 8)</i>		<i>t</i> ²
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Approach responses										
LA	48.7	13.12	47.9	8.69	0.19	51.5	8.21	37.5	5.16	4.51***
PR	50.3	9.39	51.4	6.40	0.36	52.4	6.56	47.9	7.42	1.66
SG	49.0	10.61	48.5	7.58	0.14	50.0	8.53	43.5	4.28	2.05*
PS	47.4	10.26	47.1	9.59	0.07	48.8	8.97	43.3	10.90	1.45
Total ^b	29.7	16.32	30.0	11.01	0.06	33.3	11.58	19.9	7.24	3.08**
Avoidance responses										
CA	50.7	12.20	44.7	6.23	1.86	45.7	8.78	46.4	5.48	.22
AR	56.9	12.60	48.4	7.43	2.34*	50.5	9.83	47.9	7.10	.70
SR	57.7	13.59	47.8	7.90	2.56*	51.3	10.45	45.4	7.27	1.49
ED	59.4	10.47	46.1	7.96	3.73**	50.4	10.34	42.0	4.72	2.22*
Total ^b	37.6	17.55	21.9	8.74	3.40**	26.5	13.75	19.8	5.95	1.34

¹ $df = 33$; ² $df = 32$

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

^a Standard scores ($M = 50$ $SD = 10$) for the 8 sub-scales of the Coping Response Inventory-Youth Form. ^b Raw scores

LA = Logical analysis; PR = Positive reappraisal; SG = Seeking guidance & support; PS = Problem solving; CA = Cognitive avoidance; AR = Acceptance or resignation; SR = Seeking alternative rewards; ED = Emotional discharge.

charge' in comparison to the other siblings $t(33) = 2.34$, $p < 0.05$, $t(33) = 2.56$, $p < 0.05$, and $t(33) = 3.73$, $p < 0.01$, respectively. Siblings who worried scored higher on 'total approach' than other siblings, $t(32) = 3.08$, $p < 0.01$. These worried siblings made more use of the coping strategies 'emotional discharge', 'seeking guidance and support', and 'logical analysis' in comparison to siblings who did not worry, $t(32) = 2.22$, $p < 0.05$, $t(32) = 2.05$,

$p < 0.05$, and $t(32) = 4.51$, $p < 0.001$ respectively (table 3).

Discussion

WELL-BEING

Although most studies indicate that siblings of children with a disability experience more problems in psycho-

logical adjustment than siblings of non-disabled children, this study found no indications of serious problems. Even so, the children who were interviewed encountered many difficulties that do not befall other teenagers. The problem situations which the children described were quite stressful. For example:

When I walk past the school with A there are sometimes older children who try to hurry us along. They ring their bicycle bells and shout, 'Hurry on with that sluggish child';

The problem was that we went for a walk in the mountains in France and at a certain point B could not go any further. We did not know whether to walk on or go back. Later it turned out we still had seven hours of walking before us;

C needed an operation. When I visited her in the hospital, I was scared at first. It looked scary. I was afraid something would go wrong.

As is clear from the examples, the stressful situations have to do with several aspects of life. Most situations dealt with illness or hospitalization of the sibling with a disability.

RELATIONSHIP WITH THE SIBLING WITH A DISABILITY

Apart from the stressful situations described above, there are also problems in everyday life. In general, the answers of the non-disabled children reflect an acceptance of their situation. For example, 'Life is as it is and if I can be of any help I will gladly do it'. However, they sometimes have trouble doing the things other siblings usually do together. The most difficult aspects of everyday life are doing things together and communication. Doing things together often asks for ingenuity in finding adaptations. Outings with the child with a disability may take additional preparation, energy and time. Not surprisingly, the siblings try less hard to adapt activities they themselves dislike.

Communication is often difficult. One reason for this are speech impairments. Another often cited reason is that the worlds of the siblings are too far apart. The child with a disability may have different interests, cognitive problems, or may have fewer opportunities to take part in things. Brothers and sisters hesitate to talk about their 'crushes' because the child with a disability has not yet experienced similar things.

RELATIONSHIP WITH PEERS AND EXTERNAL COMMUNITY

One of the problems discussed in the literature is that having a sibling with a disability acts as a hindrance to

friendships, especially to friendships with members of the opposite sex.¹⁸ Results of this study did not show the existence of such a problem. One of the reasons may be that our respondents were relatively young ($M = 14.1$ years), i.e. at an age where steady relationships with members of the opposite sex are not yet expected. Furthermore, most of the literature originates in the United States and cultural differences regarding dating may account for these conflicting findings. If the pressure to date begins at a younger age for children of the United States, than for children in the Netherlands, we might expect to see this discrepancy in the results.

Be it that the relationship with friends seems to present few problems, the relation with strangers bothers many of the interviewed youngsters. 'People keep looking. What they see is uncommon, so they look. It annoys me if people look back for a second look'. 'People often help too quickly or too slowly. They misjudge the situation'. Stares and unpleasant remarks make it more difficult for siblings to go out with the child with a disability. It is understandable that especially for teenagers standing out in a negative way is very unpleasant.

Siblings reported to have acquired a different perspective on other people, especially people with disabilities, resulting in an increased insight. This finding supports earlier findings that siblings of children with disabilities are more mature, more tolerant and more altruistic.^{3, 4, 15}

RELATIONSHIP WITH PARENTS

In general, the respondents expressed a large degree of appreciation for their parents. They acknowledged that their parents tried to give their children an equal amount of attention and appreciated them for it. They also noticed that, despite their attempts, the parents did not always succeed in this. Their answers indicate that they try to accept the occasions when the child with a disability gets more attention, but that it sometimes bothers them. Siblings older than the child with a disability were most aware of differences. The literature suggests that differential treatment can be seen as a risk factor.^{5, 9, 18, 22, 23} As the siblings in our sample acknowledged the parental efforts to limit differences in treatment, this may in part explain the relative absence of serious problems. Furthermore, as previously reported, we found a positive attitude of the parents towards the child with a disability.²⁶ This may be a factor in the apparent positive adaptation of the siblings in this sample.^{4, 5, 15, 17, 18, 21}

The children have a positive view of the communication with their parents. Most children said they can tell

everything to at least one of their parents. According to the literature, open communication between parents and children is an important factor in preventing psychological problems in siblings.^{18, 20, 27} This may also explain why few serious problems were reported in this study. The children seem to regard it as a natural phenomenon that they should sometimes care for their disabled brother or sister, however, we did not find evidence for compulsive caregiving as mentioned by Crittenden.¹⁶ The children report a choice in whether or not they care for their brother or sister with a disability and besides, they do not need this device to get attention from their parents who are themselves anxious to distribute their attention fairly.

PROBLEMS AND COPING

The problems that were described had to do with three different types of problems: medical emergencies, reactions of outsiders, and worries about the present or future. It is well known that the complications of spina bifida often necessitate treatment and even hospitalization. Diagnosis may therefore be a proxy for the frequency and/or severity of health problems. However, in this sample no differences in type of problems were found between siblings of children with spina bifida, cerebral palsy or multiple impairments.

As a group siblings did not differ from the norm in their coping responses. Within the group of youngsters, however, there were differences in ways of coping: sisters use more 'approach' coping strategies than brothers, that is, they tried to solve their problems instead of finding ways to live with it. The literature suggest that approach coping strategies are associated with better psychological outcomes than avoidance strategies.^{28, 29}

LIMITATIONS

When selecting the families, three inclusion criteria were used: membership of the BOSK, the physical disability and the age of the non-disabled child. The sample might not completely reflect the diversity of all Dutch families with children with physical disabilities, therefore caution in interpreting the results is required. The parent's education level is higher than generally found in the Dutch norm population. A degree of self selection is likely to have occurred. There was an overrepresentation of two parent-families. It is possible that families with many problems decided not to participate. All parents were members of the BOSK, a parent society. Parents affiliated with such a society may have been more

conscious of problems associated with raising a child with a disability. However, it is not to be expected that these parents would be better informed about possible problems between siblings because this topic is new for the BOSK as well, and thus far had not received systematic attention. Furthermore, there are limitations to the extent in which the coping results can be interpreted, as we had to use the original (i.e. American) norms for the CRI-YF.

QUESTIONS

In answering some questions, this study has raised new ones. The first question has to do with differences between different subgroups in this sample. Results of this study indicated that siblings of a child with spina bifida and siblings who are older than the child with a disability have a more difficult time than other siblings. What causes these differences? A larger study could shed further light on these questions. A second question refers to the relative absence of reports of negative feelings. To what extent can the youngsters with and without a disability show any negative feelings? The respondents displayed a very social and caring attitude. This supports earlier reports of positive outcomes associated with being raised with a child with a disability.^{3, 4, 15} However, it is not clear if this behaviour coincides with a feeling of well-being in the youngsters themselves or if this caring and understanding attitude has potential harmful effects as well. For example, Gath and Gumley reported that mothers of children with Down syndrome assumed that their other children had hidden emotional problems despite their normal scores on the Rutter behaviour scale.³⁰ The last question concerns the children with a disability. Very little research has been done on their opinions and therefore very little is known about their point of view. As relationships involve the perspective and feelings of two people, it would be important to know more about how the child with a disability views the family, etc.

CLINICAL IMPLICATIONS

Most siblings were able to cope with the help they received from their immediate environment. However, nine children reported that they would like help from others. Perhaps parent organizations could assist in providing help for these youngsters. The following are some suggestions about the form such help could take: The children were asked what they knew about their sibling's disability. Although all of them had some idea,

many were not able to be specific in their answers. This, in addition to the fact that children asked so many questions about medical matters, suggested that the children may have a need for information. Easy access to information for the siblings is needed. One of the respondents (whose sibling was multiply impaired) had attended a meeting of siblings of children with mental disabilities. Her enjoyment of this contact with other siblings suggests the value of such meetings for siblings of children with physical disabilities.

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